

STARS

University of Central Florida
STARS

Honors Undergraduate Theses

UCF Theses and Dissertations

2016

Black Caregiver Responses to and Perceptions of Signs, Symptoms, and Treatments at the End of Life

Samantha M. Sermarini
University of Central Florida



Part of the [Other Nursing Commons](#)

Find similar works at: <https://stars.library.ucf.edu/honorsthesis>

University of Central Florida Libraries <http://library.ucf.edu>

This Open Access is brought to you for free and open access by the UCF Theses and Dissertations at STARS. It has been accepted for inclusion in Honors Undergraduate Theses by an authorized administrator of STARS. For more information, please contact STARS@ucf.edu.

Recommended Citation

Sermarini, Samantha M., "Black Caregiver Responses to and Perceptions of Signs, Symptoms, and Treatments at the End of Life" (2016). *Honors Undergraduate Theses*. 17.
<https://stars.library.ucf.edu/honorsthesis/17>



BLACK CAREGIVER RESPONSES TO AND PERCEPTIONS OF
SIGNS, SYMPTOMS, AND TREATMENTS AT THE END OF LIFE

by

SAMANTHA SERMARINI

A thesis submitted in partial fulfillment of the requirements
for the Honors In the Major in Nursing
in the College of Nursing
and in the Burnett Honors College
at the University of Central Florida
Orlando, Florida

Spring Term 2016

Thesis Committee Chair: Dr. Norma Conner

ABSTRACT

Individuals in the final stages of life are often cared for by informal caregivers whose interpretation of the patient's signs, symptoms and treatment needs and options may be incongruent with that of healthcare providers (Docherty et al., 2008). Nurses need to fully understand the scope of this disparity. The purpose of this study was to determine how Black caregivers interpreted signs, symptoms, and treatments for symptom relief during the last months of their loved one's life. The effect on caregiver decision making was explored. This project is a secondary analysis of preexisting qualitative data. Transcripts from 5 focus groups encompassed 53 participants. All participants were Black and informal caregivers or decision makers for a loved one at their loved one's end of life. Eighty-seven percent of caregivers were female, and a majority had a high school education. The mean age was 66. Transcripts were coded for themes independently by two researchers. To allow for the most open interpretation, no *a priori* set of codes was utilized. 3 main categories of signs, 4 main categories of symptoms, 4 themes of the interpretation of signs and symptoms, 4 main categories of treatments and interventions, 5 themes of the interpretation of treatments, and 3 themes describing the effect of signs, symptoms, and treatments on decision making were identified. Case examples of the caregiver interpretation process are included. Health care providers need to provide time, clear and simplified language, and additional explanation in communication. Further research combining health literacy measures and qualitative data on interpretations should be conducted.

DEDICATION

For my mom and dad. Thank you for the endless support and encouragement and for teaching me that I can do whatever I set my mind to.

ACKNOWLEDGEMENTS

I would like to thank to my thesis chair, Dr. Norma Conner, for encouraging me and being so involved in this project. I am thrilled to have had the opportunity to work with you and learn so much in the process.

Thank you to my committee members Dr. Victoria Loerzel and Dr. Daniel Paulson. I am so appreciative of your time, interest in the project, and valuable insight.

I would also like to thank the Burnett Honors College for financial support through the Honors in the Major Scholarship.

Thank you to the informal caregivers who attended focus groups to provide data I used in this research. Participation in the study took time and was emotionally challenging for some participants. However, their contribution of discussing caring for their loved one at the end of life allows for greater understanding of their experiences and will allow nurses and healthcare providers to better provide care in the future.

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION	1
Problem	1
Significance.....	3
Purpose.....	3
Research Questions	4
CHAPTER 2: REVIEW OF LITERATURE.....	5
Family Interpretations of Signs and Symptoms at the End of Life.....	5
Signs and Symptoms Causing Stress	5
Interpretation of Cognitive Changes at the End of Life.....	6
Variations in Interpretation of End of Life Signs and Symptoms	6
Effect of End of Life Signs and Symptoms on Family Members	7
Family Responses to and Interpretations of Treatments at the End of Life.....	7
Misunderstandings Surrounding Treatments at the End of Life	7
Treatments As a Source of Stress	8
Distrust of the Healthcare System.....	8
Decision Making Related to End of Life Signs, Symptoms, and Treatments	9
Summary	10
CHAPTER 3: METHODS AND PROCEDURES	12
Design	12

Human Subjects	12
Sample and Setting	12
Procedure	13
CHAPTER 4: FINDINGS	14
Signs and Symptoms Discussed by Caregivers	15
Interpretations of Signs and Symptoms	16
Misunderstanding Signs and Symptoms	16
It's Not As Bad As it Seems	16
Loved One is Unsafe Due to Signs and Symptoms	18
Enduring or Ignoring Emotional and Psychological Symptoms.....	19
Treatments and Interventions Discussed by Caregivers	20
Interpretations of Treatments and Interventions	21
Caregiver Misunderstandings Surrounding Treatments and Interventions	21
Treatments Causing a Struggle for Control between Caregiver and his or her Loved One .	22
Inadequate Communication in Healthcare.....	24
Lack of Compassion in Healthcare	25
Interpretation of Informal Caregiving As a Treatment Option	25
Effect of Signs, Symptoms, and Treatments on Decision Making	26
Decisions to Accommodate	26
Decisions to Stop or Alter the Course of Treatment Based on Signs and Symptoms	27

Caregivers Deciding to Take on Extra Roles.....	28
Case Examples of Caregiver Interpretation Process	29
CHAPTER 5: DISCUSSION.....	33
Discussion	33
Study Limitations.....	37
Sample.....	37
Methods.....	38
Clinical Implications	38
Educational Implications	40
Research Implications	41
APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVAL OF EXEMPT HUMAN RESEARCH.....	44
APPENDIX B: FOCUS GROUP QUESTIONS FROM THE ORIGINAL STUDY.....	46

LIST OF TABLES

Table 1: Caregiver Demographics	14
Table 2: Signs Discussed by Caregivers	15
Table 3: Symptoms Discussed by Caregivers.....	16
Table 4: Treatments Discussed by Caregivers.....	21

CHAPTER 1: INTRODUCTION

Patients approaching the end of life are understood to have a great likelihood of death within 12 months (General Medical Council, 2010). Most often these patients will be closely surrounded by informal caregivers. The National Hospice and Palliative Care Organization (NHPCO) describes caregivers as those who support individuals who need assistance (2014). Yet few caregivers are previously prepared to take on this role (NHPCO, 2014). In the United States, 65.7 million adults act as informal caregivers for another adult who is aged, ill, or disabled (Family Caregiver Alliance, 2012). 43.5 million people care for somebody over the age of 50 (Family Caregiver Alliance, 2012). As of 2012, 13% of informal caregivers were African-American (Family Caregiver Alliance, 2012). While 13.2% of the population of the United States was Black in 2013, Black people represented only 8.4% of hospice patients in 2014, down from 8.6% in 2012 (NHPCO, 2014; U.S. Census Bureau, 2015). Compared to White people, Black people are not as likely to use home or community based care, and it has been suggested that barriers to access have caused Black people to not frequently utilize these alternatives to nursing homes (Feng, Fennell, Tyler, Clark, & Mor, 2011). With less use of hospice, home, and community services, decreased access to healthcare, and higher rates of poverty, more family members may be taking over the role of informal caregiver in Black households.

Problem

The caregiver is often responsible for making decisions for his or her loved one (Conner & Chase, 2015). For patients who have no formal statement of end of life wishes, the caregiver

may have little guidance in decision making. In these situations more than others, caregivers may have to rely on signs and symptoms to make decisions about patient care, treatment, or changing patient status.

Misperceptions of end of life signs and symptoms among informal caregivers can lead to uninformed decision making, and the inability of patients to experience a good death. Nurses and other healthcare providers need to fully understand the scope of caregiver misperceptions at the end of life, and identify areas for educational interventions that can lead to more positive outcomes for patients and their caregivers during the dying process. Additionally, it is important to understand how signs, symptoms, and treatments are perceived so that nurses can be sensitive to the needs of patients and their families to allow them a more positive death and grief experience.

Additionally, the number of Black nursing home residents has been increasing while the percentage of White nursing home residents decreased from 1999 to 2008 (Feng, Fennell, Tyler, Clark, & Mor, 2011). It may be beneficial to understand the catalysts to caregiver decision making, including choosing to place their loved one in a nursing home. Perceptions of end of life signs and symptoms could play a part in this decision.

Black people remain underserved by hospice, home, and community based health services (Feng et al., 2011; NHPCO, 2014). Without formal support services during the dying process, Black patients are at even greater risk for not having a good death. Black caregivers who do not have the benefit of formal support from hospice or other services may lack the information to correctly interpret signs and symptoms experienced by their loved ones at the end

of life. Further understanding is needed about specific perceptions of signs and symptoms of death and dying among Black caregivers.

Significance

Forty-one percent of Black informal caregivers assisted with 4 or more activities of daily living for their loved ones, compared to 28% of White caregivers and 23% of Asian-American caregivers. Additionally, Black caregivers spend on average 20.6 hours per week on caregiving activities (Family Caregiver Alliance, 2012). Black caregivers are more likely than the general population to live with the loved one to whom they provide care (Family Caregiver Alliance, 2012).

Older Black people have low access to healthcare, with 96% denying having a regular health care source from 2006 to 2008 (U.S. Department of Health and Human Services, 2010). Only 35% of older Black people had private supplemental health insurance in addition to Medicare compared to 50% of all older Americans regardless of race (U.S. Department of Health and Human Services, 2010). Additionally, the rate of poverty for Black people over 65 is 20%, whereas the national average for all races of that age group is 9.7% (U.S. Department of Health and Human Services, 2010). This reduces the available financial resources to acquire additional caregiving assistance.

Purpose

The purpose of this study was to determine how Black caregivers responded to and perceived signs, symptoms, and treatments for symptom relief during the last months of their loved one's

life. Black caregivers' understanding of and meaning attributed to signs, symptoms, and treatments of their terminally ill loved ones were identified.

Research Questions

The following research questions guided data analysis:

- How did the caregiver interpret signs and symptoms?
- How did the caregiver interpret the treatments or interventions surrounding their loved ones symptoms?
- How did their loved one's signs and symptoms affect caregiver decision making?

CHAPTER 2: REVIEW OF LITERATURE

Family Interpretations of Signs and Symptoms at the End of Life

Signs and Symptoms Causing Stress

Family caregivers have been shown to be hypersensitive to signs and symptoms preceding the end of life phase (Fluur, Bolse, Strömberg, & Thylén, 2014). The focus on signs and symptoms does not stop when their loved one approaches the end of life. For example, Angelo and Egan (2015) conducted a photovoice study involving White family caregivers of end of life patients with renal disease. Caregivers took photographs to represent stressful events involved in caring for their loved one and later discussed the photographs in an interview. Multiple caregivers told stories about their photos that related to end of life symptoms causing their stress, including their loved one becoming incontinent, having respiratory difficulties, experiencing anorexia, and struggling with activities of daily living (Angelo & Egan, 2015). Additionally, Penman and Ellis (2015) reported caregivers have identified fear of not only their loved one's death, but also fear of not being able to relieve symptoms, their loved one collapsing or falling down, and their loved one becoming cognitively impaired. In a study conducted by Nobel, Kelly, and Hudson (2013), caregivers of a family member with stage 5 kidney disease who was not undergoing dialysis frequently reported anxiety due to signs and symptoms and the anticipation of a decline in their loved one's condition. These studies show that caregivers perceive end of life signs and symptoms as a source of stress, fear, and anxiety.

Interpretation of Cognitive Changes at the End of Life

Family members reported a variety of perceptions and emotions surrounding cognitive changes at the end of life. For example, some caregivers reported their loved one's cognitive impairment caused them to feel isolated, alone, or abandoned (Sanders, Ott, Kelber, & Noonan, 2008). Godwin and Walters (2009) interviewed family caregivers of individuals with advanced dementia in order to learn about their views and experiences with end of life care. One family member believed his loved one may have lost the ability to comprehend death, which the authors called "the common underestimating of the abilities of people with advanced dementia" (Godwin & Waters, 2009, p. 267). In a different study, a family member whose loved one was dying of heart failure in a nursing home noted their loved one's confusion affected how the patient was able to communicate her symptoms and make decisions about care (Kaasalainen et al., 2013).

Variations in Interpretation of End of Life Signs and Symptoms

At times, family perceptions of end of life signs are even contradictory. In one study, only some family members reported feeling distressed listening to the death rattle, a distinctive, noisy breathing sometimes present when an individual is near death (Wee, Coleman, Hillier, & Holgate, 2006b). A follow up study delved deeper into family interpretations; while some viewed the sound as very distressing and likened it to "drowning" or "choking," others were comforted knowing that death was finally approaching (Wee, Coleman, Hillier, & Holgate, 2006a, p. 179). Further, one participant whose loved one did not present with a death rattle expressed regret that they did not have that sign to know how close death was, as it may have allowed the family to stay with him during his final hours (Wee et al., 2006b). Clearly, the

perception of some end of life signs can differ greatly and have very different meanings among family members.

Effect of End of Life Signs and Symptoms on Family Members

Family members perceived their loved one's signs and symptoms as affecting many aspects of life. Decreased functioning was viewed as interfering with relationships (Angelo & Egan, 2015). End of life neurological signs and symptoms have also been shown to result in changing roles and a struggle over loss of control for both the dying person and his or her caregiver (Draper, Day, Garrood, & Smith, 2013). In one study, many family members viewed their loved one's end of life heart failure symptoms as restrictive (Kaasalainen et al., 2013). As a result, the family and patient chose to focus care around symptom management and treatments like exercise to decrease shortness of breath so that physical activities would be less limited (Kaasalainen et al., 2013). On the other hand, Draper, Day, Garrood, and Smith (2013) found some family members attempted to downplay or ignore signs and symptoms of terminal neurological illnesses as a form of denial of their loved one's impending death.

Family Responses to and Interpretations of Treatments at the End of Life

Misunderstandings Surrounding Treatments at the End of Life

Caregiver perceptions of end of life symptom treatments appeared occasionally in the literature, and the caregiver's interpretations were often misinformed. Family members of a patient with an implantable cardioverter defibrillator were frequently fearful of the device and misunderstood its limits (Fluur et al., 2014). Many were completely uninformed of the

implications for end of life and palliative treatments, including that the device could be turned off and not cause immediate death (Fluur et al., 2014).

Multiple family members interviewed in a study by Nobel, Kelly, and Hudson (2013) did not understand why their loved one with stage 5 chronic kidney disease was not being treated with dialysis while undergoing palliative care. Family members in this sample also misunderstood symptoms at their loved one's end of life. For example, one caregiver thought pruritus was a symptom caused by exacerbated kidney failure when it was actually from eczema and completely unrelated to the underlying disease (Noble, Kelly, & Hudson, 2013).

Treatments As a Source of Stress

Angelo, Egan, and Reid's (2013) research revealed palliative treatments were also a source of stress for caregivers when they were the ones responsible for administering medications. They worried about giving the wrong amount of pain medication and not knowing how to respond if they gave the wrong amount. Because their loved ones were often receiving new medications, managing the drug regimen caused continuous stress (Angelo, Egan, & Reid, 2013). No participants in this study identified as Black.

Distrust of the Healthcare System

The literature revealed that caregivers repeatedly expressed doubt in the healthcare system that was responsible for identifying and managing signs and symptoms. They cited concerns over staff's lack of knowledge about their loved one's condition and not recognizing signs and symptoms early on (Kaasalainen et al., 2013). Another study showed family member's concerns about the staff not dealing with symptoms appropriately due to lack of familiarity and

understanding of individuals with dementia (Sanders et al., 2008). Family members in both studies reported poor or inconsistent communication with healthcare workers.

Decision Making Related to End of Life Signs, Symptoms, and Treatments

Caregivers may be influenced in decision making based on their loved one's end of life signs and symptoms. Gao et al. (2013) showed in a longitudinal cohort study that caregiver's were less likely to choose end of life care that was consistent with the patient's preferred intensity if the patient was no longer fully cognitively aware. Signs and symptoms may also influence decisions about care when the caregiver feels he or she can no longer manage their loved one at home. Harrington, Mitchell, Jones, Swetenham, and Currow (2012) found that relief was a common theme among caregivers who transitioned their loved one to inpatient care. The transition allowed their symptoms to be managed, and the caregiver did not have to cope with the signs and symptoms constantly and in isolation. One participant noted that in an inpatient facility, he or she did not have to see the loved one "suffer and [get] weaker and weaker" (Harrington, Mitchell, Jones, Swetenham, & Currow, 2012, p. 551). Noble, Kelly, and Hudson (2013) showed that frequently, the decision to transfer to inpatient or long term care was related to a specific incident when the caregivers realized they would not be able to care for their loved one on their own. Symptoms like extreme fatigue or weakness could be the cause of these events. For example, when one woman was unable to get up from using the restroom for hours, her caregiver decided she had to transition to a nursing home because she could no longer manage the weakness her disease was causing (Noble et al., 2013).

Summary

Family perceptions of and responses to signs, symptoms, and treatments have been observed by various researchers through primarily qualitative data. Signs and symptoms at the end of life have been shown to cause the caregiver stress, anxiety, and fear (Angelo & Egan, 2015; Noble et al., 2013; Penman & Ellis, 2015). Cognitive changes at the end of life led to feelings of isolation for the caregiver, and family members discussed their loved one's confusion as causing problems in communication (Kaasalainen et al., 2013; Sanders et al., 2008). Additionally, family members reacted variably to the death rattle; some were distressed while others were indifferent or wished the sign had been present as a warning that death was near (Wee et al., 2006a; Wee et al., 2006b). Decreased functioning caused role changes, influenced how caregivers and patients sought treatment, and were perceived by the family as affecting the patient's relationships (J. Angelo & Egan, 2015; Draper et al., 2013; Kaasalainen et al., 2013).

There are some noteworthy family perceptions of treatments in the literature. For example, implantable cardioverter defibrillators were often misunderstood by family members (Fluur et al., 2014). Symptoms and discontinuation of treatment also caused confusion for the families of patients with stage 5 chronic kidney disease not undergoing dialysis (Noble et al., 2013). Additionally, caregivers reported administering medications caused stress (J. Angelo K. et al., 2013). Family members often conveyed concern over healthcare workers lack of knowledge about signs, symptoms, and their loved one's conditions (Kaasalainen et al., 2013; Sanders et al., 2008).

Multiple studies point to signs and symptoms influencing caregiver decision making at the end of life (Gao et al., 2013; Harrington et al., 2012; Noble et al., 2013). There is a paucity of information on Black caregivers' interpretations of end of life signs, symptoms, and treatments. Little research has been published that explores the viewpoints of Black caregivers on these topics. Additionally, Black people were underrepresented in some of the articles cited (Sanders et al., 2008; Wee et al., 2006a; Wee et al., 2006b).

CHAPTER 3: METHODS AND PROCEDURES

Design

A secondary analysis was conducted using conventional content analysis. This study utilized preexisting qualitative data. Transcripts from five focus groups of a previous study on caregiver decision making were independently coded by the student and thesis chair for themes pertaining to caregiver interpretation of signs, symptoms, and treatments provided and the effect of these on caregiver decision making. The codes were then compared and grouped either to consolidate or expand from the initial themes. Aside from the initial research questions no *a priori* set of codes or theory guided the data analysis.

Human Subjects

IRB approval was obtained for the original study. The current study received an IRB determination of exempt human research (Appendix A). The transcripts of the focus groups were de-identified. In the original study, caregivers received a \$20 stipend for participating and were able to withdrawal from the study at any time without losing the compensation.

Sample and Setting

The study data were originally collected via five, 90-minute focus groups. All 53 participants were Black and recruited from 3 area Black churches in two central Florida counties. Criteria for participation in the original study were Black informal caregivers and decision-makers of terminally ill loved ones, English speaking, and at least 18 years of age. Participants

were invited to take part in the study by an informal leader of the church community. Care recipients included parents, aunts, spouses, and siblings. The focus group sessions were conducted at the churches.

Procedure

The process for analysis mirrored those of the conventional content analysis (Hsieh & Shannon, 2005; Vaismoradi, Turunen, & Bondas, 2013). An inductive approach was utilized, as there was little prior research and no theory to adequately describe caregiver interpretations of signs, symptoms, and treatments. This method allowed for a lot of freedom in data interpretation and the natural emergence of themes, as no *a priori* set of codes was used. The data were analysed and organized into themes based on interpretation of the data's content. Each of the five transcripts was coded independently of the other transcripts.

In the preparation stage of analyses, the transcripts were read multiple times taking into consideration the three guiding questions. This was in order to get an impression of the data as a whole. In the organizing phase of analysis, open coding began. Initially, signs and symptoms were coded. In a meeting with the thesis chair, a review was conducted to expand on the caregiver's understanding of the signs, symptoms, and treatments identified. Interpretations and decisions were then coded. Codes were next organized and grouped under potential themes that emerged. These codes were further organized and consolidated, and a meeting was conducted in which grouping of codes and themes were verified by the thesis chair and revisions were made. Next, case examples were extracted from the data that best showed the interpretation and decision making process of caregivers.

CHAPTER 4: FINDINGS

Demographic data of the participants in the original focus group study, which provided the data for this study, are presented in Table 1. A total of 53 participants provided data for the study. All participants were Black, were at least 18 years of age, and were informal caregivers or decision makers for a loved one at their loved one's end of life. The mean age of participants was 66 years. The majority of participants were female and had at least a high school education. The majority of caregivers represented were Christian. The plurality were married and did not live with the loved one they cared for (Table 1).

Table 1: Caregiver Demographics

<i>Measure</i>	<i>Frequency</i>	<i>Percent</i>	<i>Mean</i>	<i>SD</i>	<i>Range</i>
Age, years			65.79	13.58	28-88
Education length, years			13.57	4.26	
Gender:					
Male	7	13.2			
Female	46	86.8			
Religion:					
Christian	48	92.3			
No religion	1	1.9			
No data	3	5.8			
Marital Status:					
Single/Divorced	9	17.3			
Married	24	46.2			
Partnership	1	1.9			
Widowed	18	34.6			
Patient and caregiver reside together:					
Yes	19	36.5			
No	25	48.1			
Other	2	3.8			
Caregiver role expectation:					
Yes	42	80.8			
No	8	15.4			
Other	2	3.8			

Note. SD = Standard Deviation

Signs and Symptoms Discussed by Caregivers

Early in the analysis process, signs and symptoms were coded. The signs and symptoms caregivers discussed were then listed in a separate document so that they could be grouped into similar categories. First, signs and symptoms were differentiated. Different types of signs were then identified and grouped accordingly. Signs discussed by caregivers fell into four categories: cognitive signs, functional signs, changes in physical appearance, and changes in communication (Table 2). Three groups of symptoms were similarly identified. Cognitive, physical, and emotional or psychological symptoms were discussed by caregivers (Table 3). Some signs and symptoms were addressed repeatedly by different caregivers, and the language the caregivers used was reproduced in the tables when possible.

Table 2: Signs Discussed by Caregivers

<i>Cognitive</i>	<i>Functional</i>	<i>Appearance</i>	<i>Communication</i>
Coma	Incontinent	Gangrene	Can't speak
In like a comatose stage	Disabled	Abscess	Wouldn't talk out loud
Diabetic coma	Could hardly get around	See a person's roof of their mouth drop to their tongue	
Wandering	Bedridden		
Wanting to leave home	Couldn't get around... couldn't do everything by herself	Weight loss ^a	
Puts aluminum foil in the microwave.... And puts something in the oven and sets that on fire	There are things that they are not able to do, the things that they used to do	Swelling	
Throwing things across the room	She would just sit there and look		
	She would just be lying there		

^a Indirect quote from the caregiver

Table 3: Symptoms Discussed by Caregivers

<i>Cognitive</i>	<i>Physical</i>	<i>Emotional or Psychological</i>
Couldn't remember	Appetite loss ^a	Angry
Forgetting	Didn't feel good	Scared
The memory is not there	Pain	Not talkative

^a Indirect quote from the caregiver

Interpretations of Signs and Symptoms

Misunderstanding Signs and Symptoms

Some caregivers had inaccurate interpretations of their loved one's signs and symptoms. For example, one caregiver revealed that their loved one had "coded." The caregiver interpreted this as his or her loved one being "dead" and that they then "came back" to life. Another instance of symptom misinterpretation involved a caregiver's skepticism when she was told her mother's leg was not broken: "I didn't even have to touch it, I can just look it and say yeah, there's a fracture there." The caregiver did not believe an x-ray was needed; their loved one's pain and swelling made her certain the bone was broken.

It's Not As Bad As it Seems

Many caregivers expressed less concern about the signs and symptoms exhibited than what a health provider may have determined was warranted. These caregivers viewed their loved ones signs and symptoms as not as bad as they seemed, or their interpretations suggested they did not understand the scope of their loved ones illness. Some of these incongruences may have been the result of a lack of understanding that their loved one was dying.

Multiple caregivers spoke of their loved one's dementia or cognitive changes seeming worse than they actually were. Some would focus on aspects of their memory that were still intact despite their loved ones declines in cognitive function. For example, one caregiver listed what her loved one could remember after having "mini strokes": "She could tell when we were born, where we live and work, who her children were." Another caregiver said, "He wouldn't talk out loud. I would have to ask him, do you know what my name is? Do you know me? He would just spell it to me. He would let me know that he knows what it is." Other caregivers believed there was more to their loved one than others might perceive. One caregiver who discussed how she had been treated poorly in the past by her mother-in-law maintained that "in the back of her mind, she remembers how she did me." Additionally, a different caregiver whose parents both had Alzheimer's dementia described her experience caring for her parents: "Sometimes it's like they don't have it, they'll do really good for a while." The caregiver also stated she believed her parents knew who she was despite the cognitive decline from their dementia. Another caregiver talked about how she would speak with her loved one and that others "say that he can hear what you're saying," even though he cannot talk and showed no indication of listening.

Some caregivers did not expect their loved one to die, despite long term or serious illnesses. One woman talked about her husband's stroke and her state of mind after being told bad news about her husband's health and prognosis. The caregiver was "in shock" at multiple points during her husband's illness, even after her husband was dependent on life support:

And then she, the nurse, came to tell me that he didn't have enough blood, he didn't even have enough blood to do the blood work required for him. After that, I'm still not seeing what they're seeing, I guess because I was in denial.... Even after I don't think I heard what they were saying because I just couldn't believe all what was happening to fast.

Another caregiver described his or her loved one's death, which had been foreshadowed with long term illness. The caregiver made the somewhat contradictory statements that his or her loved one "passed suddenly" after he was "sick off and on." Another said, "It was like the cancer that she had all of a sudden became full-blown, and it started taking her away fast." These caregivers believed their loved one's illnesses were not as bad as they seemed at the times before they died, thus their deaths were seen as unexpected to the caregivers.

Loved One is Unsafe Due to Signs and Symptoms

Multiple caregivers described their loved one's signs and symptoms as unsafe. It was very common for caregivers in this sample to have made decisions that they felt were necessary to ensure the safety of their loved one in the face of cognitive changes at the end of life.

Caregivers often discussed the feeling that their loved one was not safe staying alone in their home. One caregiver noted her loved one's forgetfulness was unsafe, as when the loved one had visitors the caregivers found the "doors are open, or she is sitting in the house with no air conditioning." Another caregiver noted his or her loved one left the stove on and had forgotten about it until the caregiver's brother found it on a visit to check up on her. Both caregivers were concerned about their loved one, and decided to have people check in on their loved one more frequently to keep them safe.

One caregiver discussed the loved one's forgetfulness as causing non-adherence to the medication regimen:

I'm constantly on the phone with her: "Did you take your medicine?" Because it's time now that she doesn't even remember and you have to fill the pill packs up per week and call her and make sure she's taking them when she needs to, and taking them right.

Although this caregiver was concerned about her loved one living alone, she respected the decision of her loved one and the loved one's husband to stay at home together. Along with calling frequently and ensuring they had their medications available, the caregiver and family increased the frequency of visits, confiscated the cars, and encouraged their loved ones to not cook in order to keep the loved ones safe despite end of life cognitive changes.

Enduring or Ignoring Emotional and Psychological Symptoms

In these cases, caregivers noted the frustration or sadness felt when trying to provide care due to the behavior of their loved ones. The emotional mistreatment that end of life caregivers endured was a common theme. The anger, frustration, and cruelty the loved ones felt may have been related to disease processes or they could have been a response to changes in their lives like increasing dependence and loss of ability to care for themselves. For example, one caregiver discussed how her loved one was frequently angry at those trying to take care of her, and she was refusing treatments and medications. When describing her loved one's anger, the caregiver stated, "I didn't let it bother me." The caregiver made sure her loved one got the treatments she needed despite the hostility.

One caregiver talked about her experience caring for her brother: “I mean he’d push every button he could, and I mean sometimes he would say things to you that would just make you want to go in the corner and cry, but you come back.” This caregiver chose to endure mistreatment because of her love and dedication to him. She also noted that her brother would sometimes feel guilty and apologize after these occasions and that he knew she would “always be there” to take care of him. Similarly, another caregiver discussed his and his wife’s poor treatment from his grandparents, who, despite needing help, did not want their grandchildren interfering with their lives. The caregiver said, “You have to get pass your feelings.... my wife will tell me, I’m not going back over there, I got treated so badly. And I’d say, baby, you have to get pass your feelings and truly love them.”

Some caregivers remarked on the frustration they felt when providing care:

Once you do this and you think you did it right, then she’ll tell you, “Well you know you didn’t do it how I wanted it to be done.”...Sometimes I have a hard time, but through it all I try to do the best I can. And with a person like that, if you say you won’t get frustrated sometimes, you’re wrong, cause you will. Even though that’s my wife.

In this quote, the caregiver chose to overlook the frustration his wife was feeling related to her loss of ability to care for herself. He acknowledged the difficulty, but he chose to not let it affect how he felt about her. He continued to care for her, trying to please her to the best of his abilities.

Treatments and Interventions Discussed by Caregivers

Treatments were coded initially along with the coding of signs and symptoms. They were then listed and grouped into categories of similar interventions. Treatments fell into four

categories: healthcare, providers, and policies; day to day care; medical treatments; and nutritional interventions (Table 4).

Table 4: Treatments Discussed by Caregivers

<i>Healthcare, providers, and policies</i>	<i>Day to day care</i>	<i>Medical treatments</i>	<i>Nutritional interventions</i>
Healthcare	Informal caregiving	Medications	Food
Nursing home	Move loved one to the home	Dilantin	Tube feeding
Hospital	Keep them at home	Diabetic medications	<i>Meal replacement shakes</i>
Home health	Visits to loved one	Surgery	
Hospice	Hygiene care	Heart surgery	
Nurse	Baths	Bypass Surgery	
Doctor	Whirlpool bath	Amputation	
Advanced directives	Cleaning and changing the catheter	They put a tube down her stomach <i>as a diagnostic test</i>	
		Dilantin level	
		Rehabilitation	
		Blood transfusion	
		Life support	
		Respirator	

Note. Boldface indicates 5 or more caregivers discussed the treatment or intervention. Italics indicates an indirect quote from caregivers.

Interpretations of Treatments and Interventions

Caregiver Misunderstandings Surrounding Treatments and Interventions

Some of the caregivers who misunderstood symptoms also had incorrect assumptions about the treatments and interventions surrounding their loved ones' symptoms. Additionally,

some caregivers seemed to believe life support would guarantee their loved ones' survival. For example, the caregiver whose loved one was "dead" and "came back" after a code did not understand the treatment nor likely its limitations. She was under the impression that, even after coding four times, her loved one would have survived the fifth code if the doctor had arrived sooner. Similarly, another caregiver was confused about her husband's condition and prognosis after a severe stroke. She recalled thinking, "He's on life support, so he'll be fine. He'll come around."

Treatments Causing a Struggle for Control between Caregiver and his or her Loved One

Often, caregivers discussed a struggle for control between them and their loved one when it came to making decisions about treatments or interventions. Many reported their loved ones had difficulty coping with the loss of independence that accompanied their end of life symptoms. Frequently, interventions like nursing home placement or increased activity of the informal caregiver were put in place in response to declining function at the end of life. This tended to cause a battle for control and independence for the loved one as the caregiver made decisions for their safety.

Some caregivers took a stand to ensure their loved one was safe at the expense of their loved one's independence:

Sometimes they would put their health, or their independence in front of their health. So you would have to come in and say look, this has gone too far, you have to let this go. No matter what you say about your independence now, this is what has to take place.

Due to conflict with her loved ones over treatments, another caregiver expressed the distress she experienced. She was still coping with anger related to the struggle for control during the focus group session. She had encouraged her loved ones to follow the prescribed interventions at the end of life, but her loved ones were noncompliant:

It was horrible. And no matter how many times you try to direct them to do the right thing with their medications and food. It was like a constant battle; trying to tell somebody to try to live, and they just didn't choose to do it.

Other caregivers noted the frustration their loved one experienced when they were unable to do things for themselves like go grocery shopping or perform activities of daily living independently. One caregiver said:

Her husband gets really frustrated and upset because he can't take his wife to the doctor and he can't you know, drive himself, and it just bothers him that he can't do these things. He finds it hard to find people to wait on him or do the things that he used to do.

As time went on and their loved ones were unable to live by themselves, some caregivers and their loved ones struggled for control concerning living arrangements. There were multiple instances of the caregivers' loved ones wishing to stay in their homes despite declines in cognitive or physical functioning. One caregiver discussed her parents' refusal to move out of their house. Her parents still wanted their independence and their own space despite the caregivers concerns about safety. A different caregiver revealed, "When you take their independence away, that's the last little speck of dignity they have. And by me putting her [in a nursing home] I, I guess you can say that I violated her dignity." Despite the caregivers wanting

their loved ones' independence and dignity to be maintained, they did not believe allowing them to live alone was in their loved ones' best interest.

Inadequate Communication in Healthcare

Caregivers often discussed communication inadequacies they experienced when dealing with healthcare workers and organizations at their loved one's end of life. One caregiver expressed concern over the use of medical terminology, including the commonly used word "stethoscope":

It's okay to use the medical terminology, but its so confusing. I mean, people use the word to try to impress you like they, you know, stethoscope... It's like the older people, you know, and maybe people my age and younger, they don't understand the terminology.

Other caregivers were also concerned with communication among healthcare workers and facilities. Repeated paperwork at each facility frustrated one caregiver: "Every hospital I went to, nobody communicates with nobody. Why don't you just fill out another one?"

Another caregiver told a story about somebody in the hospital coming to talk with her about placing her husband in a nursing home. She stated she had been unaware that this was something that needed to be discussed, as she believed her husband would be able to come home with her when he left the hospital:

So I told his doctor at that time, and he said, she had no right to come and talk to you, so I never saw any more of her at all. They had papers for me to sign, and I said, no, I don't know what all this stuff is because he is coming home.

At that time, the caregiver had been unsure of the patient's plan of care and realistic expectations, and they did not believe discussions of long term care had been properly communicated to them or to the physician.

Lack of Compassion in Healthcare

Caregivers were often unhappy with the lack of compassion they found from healthcare workers and the paperwork involved at their loved one's end of life. Some caregivers felt the healthcare workers were insensitive regarding timing. For example, a caregiver expressed confusion and frustration regarding a hospital system's approach to delicate situations and difficult end of life decisions:

My experience was that they come at a sensitive time when they're going into a coma and they come out rushing to you, here sign this paper. Why is it that they do that at that point? Why can't a person be given those papers at the beginning when things aren't at a grave position?

Another caregiver reported the callousness of the paperwork they were given when asked to make decisions for their loved ones: "It's no compassion either. I mean it's just like, okay whatcha wanna do? You wanna live or you wanna die?"

Interpretation of Informal Caregiving As a Treatment Option

Caregivers chose to provide care based on their relationships with their loved ones and their interpretations of the informal caregiver role. Many caregivers spoke of the care they provided their loved ones at the end of life as a duty, and often their interpretations were related to a biblical or religious responsibility to provide care. For example, one caregiver reasoned:

I think being a Christian, you have to do what you can to help one another. I was brought up in the time that we didn't have nursing homes and those kinds of things, so when it became time to take care of your loved one or a friend, you did for them. So I think that still goes today, that you have to do your part in helping somebody else. Whether is going to see them, feed them, or bathe them or those kinds of things.

Another said that despite the hardship and stress from being a caregiver, "I cope with it, because that's my wife, and the bible says we should stay together until death do we part, whether we sick or whatever, and this is what I do."

Other caregivers described views of informal caregiving as a treatment option that were unrelated to religion. Some interpreted caregiving as an act of goodwill. For example, one caregiver said, "If the situation was in reverse, we know [our loved one] would do this for us." Another noted, "It was hard, but I would like someone to help me if I was down." The caregivers were all motivated to be involved in their loved one's treatments, but duty was a theme often entwined in their stories.

Effect of Signs, Symptoms, and Treatments on Decision Making

Decisions to Accommodate

Numerous caregivers discussed changes in care related to their loved ones signs and symptoms. As their loved ones symptoms increased and functioning decreased, many caregivers gave up their previous way of life to care for their family member. Many provided frequent visits to their loved one as the diseases progressed. Others had family members move in with them or

decided to move or travel frequently in order to provide care. One family would trade off who stayed home with their loved one and who went to church in order to ensure their loved one was cared for, as she could not attend church since she became incontinent.

Another decision a caregiver made involved changing how she would care for her loved one in order to decrease her loved one's anxiety. The caregiver spoke about her loved one's fear of the nurses and of receiving care from individuals outside of her family while she was in the hospital. The caregiver revealed that he or she put "life on hold" while his or her mother was in the hospital in order to stay during the nights to provide comfort and care. The caregiver saw staying at the hospital was a way to reduce fear in her mother, so she gave up her way of life to help accommodate for her mother's fear.

Decisions to Stop or Alter the Course of Treatment Based on Signs and Symptoms

Often, the caregivers' interpretations of signs and symptoms would influence their decisions to stop or alter the course of their loved ones' treatment. For example, one caregiver explained her decision to stop her loved ones' treatments:

Both of them went into like a comatose stage, brain cells were just like deteriorating, so I know both of them, neither one would want to be in that type of situation. So I just was like, let them go.

Because she saw her loved ones were in a "comatose stage," she determined her loved ones would want treatment discontinued. This caregiver also stated "there was no decision making" in caring for her loved ones.

Other caregivers treated their loved ones differently as signs and symptoms progressed, and this altered how they cared for them. A caregiver decided she could move her mother with dementia closer in order to care for her when her mother was “on her way out, you know, forgetting about home.” Another caregiver decided her loved one would have to go to rehab if signs and symptoms of his or her loved one’s heart condition did not improve.

Many caregivers in the sample decided to have their loved one placed in a nursing home in response to signs and symptoms. One caregiver revealed they “couldn’t handle it anymore,” when their loved one’s wandering worsened, and they decided they could not take care of her at home. Similarly, another caregiver discussed having to put their mother, who had dementia, in a nursing home because she “got so bad” and was trying to leave the house repeatedly.

Finally, one caregiver discussed deciding to alter the way they cared for their mother as her signs and symptoms progressed. The caregiver talked about grinding up her mother’s meals so that she could eat them, and she talked about her mother eventually losing her appetite and denying food altogether. “She was like a baby, so we treated her like she was a baby,” the caregiver explained.

Caregivers Deciding to Take on Extra Roles

Informal caregivers frequently decided to take on extra roles when they provided care for their loved one. They were not only a child, sibling, or niece once they took on the role of informal caregiver or decision maker. They often assumed responsibility for food preparation, hygiene, medication administration, choosing treatments, and countless other roles. Sometimes, taking on extra roles and breaking boundaries that had existed throughout the relationship was

distressing. One caregiver discussed the change in his role caring for his mother: “It’s hard when it’s that intimate... from changing the catheter to cleaning the catheter, I did everything. And that really hurt.”

While treatments and interventions were prescribed by healthcare providers, the caregivers were frequently responsible for hands on care and administering treatments, even in the hospital setting. Often, this was a result of the end of life patient’s preference. For example, one caregiver discussed administering a blood transfusion herself while in the presence of her loved one’s hospice nurses: “Even though they were there, I still did everything. Because she did not allow anybody else to do anything.” Another caregiver provided all the care he could for their father in order to respect his wishes: “He didn’t want anybody from the outside to come in and do our responsibilities, because my father said that this was our family.” Sometimes, a caregiver would have to provide care because their loved one was refusing care or treatments from hospital staff. “The hospital took a lot of abuse, cause I mean, she was like, she just was not having it,” one caregiver remarked. “If you’re not the family, you can’t do it.”

Case Examples of Caregiver Interpretation Process

Two notable case examples highlight the decision making process that caregivers underwent as they observed their loved ones signs and symptoms. Their interpretations framed their choices about end of life care and treatments. The first case involved a woman’s informal caregiving and decision making for her mother, who resided in a nursing home. The caregiver, who had not seemed to fully understand the severity of her mother’s condition, had healthcare providers recommend amputation for “gangrene.” The caregiver discussed pressure she felt from

her family and healthcare providers regarding deciding on whether or not to treat the “gangrene.” Holding back on the decision to amputate was against the wishes of other family members. However, she stated that her mother wanted every one of the 7 siblings agreeing before any action would be taken. “If one did not agree, don’t pressure that one, because that’s the way the Holy Spirit is telling you to wait,” she maintained. “I had had a dream that it appeared that my mother’s leg was still there. So to me that was a message to me saying don’t do it.”

The caregiver decided to postpone amputation based on her assessment of signs and symptoms, her understanding of her mother’s condition, and her spiritual interpretation of a dream. The caregiver then described the events after her decision was made:

When they did the medication all of a sudden what they saw, that they said was the gangrene, that is was something else, some, I don’t know what they use, but how your medicines can get all mixed up, it came out like, it was something like that...So for me, it validated my presence. It made them go back and study some more, do some other things.

So it was about six months before my mother’s leg eventually was amputated.

She also discussed her interpretation of her mother’s pain in relation to the decision to amputate:

“The pain that she was having was not necessarily that you need to cut a leg off at that point.”

Her interpretations of her mother’s signs and symptoms was likely incongruent with that of healthcare providers as she refused her mother’s amputation despite their recommendation. She did not believe her mother’s condition was as dire as others, aligning with the theme, “it’s not as bad as it seems.”

A different caregiver described his time caring for his mother-in-law, who had dementia and rheumatoid arthritis, for 20 years. For two years during that time, he also cared for his mother, who had dementia. He explained that he had a harder time caring for his mother due to her tendency to wander:

My mother was worse than my mother in law because she had—she wanted to leave in the middle of the night, and she'd try to get up and get out of the house. My mother in law, she was in such bad shape she could hardly get around.

The caregiver discussed how he accommodated for the signs and symptoms of dementia by ensuring his mother was not home alone:

My brother, my sister, and I shared nights. One night, I would spend the night away from home with my mom, then my brother, then my sister. So we rotated nightly, not going to our own home but staying with our mother in her home, and make certain that she was okay.

The family realized that changes had to be made in order to keep the mother safe, as she was trying to leave the home at night. This caregiver, despite not being in good health and suffering from congestive heart failure, decided that they would go to extreme measures to accommodate for their mother's symptoms. In order to keep her safe, they decided to physically blocking the door at night so that she would not be able to leave the home. After two years of caring for his mother, the caregiver decided that the family was unable to manage the end of life signs and symptoms on their own and decided that a long term care facility would be better able to tend to her needs:

I would just lie across the front door, get a chair and lay across the front door, and as she'd come to door, I'd know to wake up. And we just couldn't handle it anymore, I didn't want to put her in the nursing home, but I just had no other choice.

CHAPTER 5: DISCUSSION

Discussion

Typically, caregivers made decisions related to signs and symptoms by first identifying and interpreting the sign or symptom. This interpretation framed how they would make decisions about treatments and interventions. Then, the caregiver evaluated their perceived options to manage the sign or symptom. Finally, the caregiver would make a decision about whether or not to initiate an intervention for the sign or symptom. Caregivers responded in many ways to the signs and symptoms they perceived, including ignoring or enduring signs and symptoms, making a decision to treat or not based on interpreting information from a healthcare provider, or coming up with their own solutions to cope with signs and symptoms.

Caregivers identified a variety of signs and symptoms in these focus groups. Signs discussed included cognitive, functional, physical, and communication changes. Cognitive, physical, and emotional or psychological symptoms were also discussed. Caregivers were cognizant of the changes they discussed, and the changes often influenced how they would provide care or make decisions.

Some signs and symptoms came up in discussion multiple times with different caregivers as they described their time caring for their loved one and making decisions related to end of life care. For example, some of the most commonly discussed end of life signs and symptoms by participants were related to cognitive changes, particularly forgetfulness and wandering. The loved ones recognized these changes as relating to end of life and often tied them to the disease

progression of dementia. A study by Helmes and Pachana (2014) on the concerns of caregivers of individuals with dementia showed that memory was rated as the activity of greatest concern, with 64.9% of surveyed caregivers reporting valid concern about changes in memory and 48.4% of caregivers saying changes in memory were their principle area of concern. Wandering was not generally regarded as being a concern in this study. Only 5.1% of caregivers reported concern over wandering. No caregivers regarded wandering as their loved one's principle symptom.

The caregivers also altered how they cared for their loved one in response to cognitive changes. This included checking up on their loved one, placing their loved one in a nursing home, or having somebody stay with their loved one at all times as safety measure. Not speaking or being in a coma was also mentioned by multiple caregivers. For some, the lack of the ability to communicate with their loved one made decision making difficult. This was problematic for caregivers who had not had a discussion about end of life preferences or plans with their loved ones or who had no advanced directives to help guide decision making,.

Treatments and interventions discussed most frequently included care from hospitals, nursing homes, and home health agencies. For both life-preserving and palliative measures, caregivers frequently turned to health care providers to manage signs and symptoms at the end of life. Oftentimes, caregivers cited their reasoning for entering a nursing home was progression of disease, including being unable to properly care for their loved one due to an increase in signs and symptoms like wandering or cognitive changes. Others responded to disease progression by deciding to care for their loved one at home rather than continuing inpatient treatment.

Life support and mechanical ventilation were also frequently discussed by caregivers. Caregivers were frequently responsible for deciding whether or not their loved one would receive these treatments and for how long. Some discussed the decisions they made were a consequence of trying to honor their loved one's wishes regarding end of life care and life support. Still, many had to rely on their own interpretation of their loved one's condition to make these difficult decisions, including examining signs and symptoms and processing information from healthcare providers. Some caregivers continued with life support for as long as possible. Others elected to avoid life support and mechanical ventilation for their loved one altogether. Loggers et al. (2009) found that Black patients were more likely than White patients to request and receive cardiopulmonary resuscitation or mechanical ventilation during their last week of life.

Based on their interpretations, caregivers drew conclusions and made decisions related to caring for their loved one. There were cases of incongruences in caregiver and healthcare provider interpretations of signs, symptoms, and treatment needs and options. Signs and symptoms were reported as perceptions rather than objective data, and the caregivers may have attached meaning contrary to that of healthcare providers. Misunderstandings of treatments and signs and symptoms at the end of life have been reported in other studies as well (Fluur et al., 2014; Noble et al., 2013).

In one of the case examples discussed, a caregiver disagreed with a nurse's assessments after the caregiver's mother fell. The caregiver insisted her mother's leg was broken despite the nurse's statement that there was no fracture. This case example demonstrates a caregiver's and a

healthcare provider's incongruent views related to signs and symptoms. The case example also provides support for findings of other studies that showed caregivers' general distrust in the healthcare system related to the ability to provide knowledgeable and competent care (Kaasalainen et al., 2013; Sanders et al., 2008).

Caregiver misinterpretations occasionally resulted in incongruences of understanding related to prognosis between the healthcare provider and caregiver. In some cases, this involved the caregiver not expecting their loved one's death. Additionally, a lack of effective communication and confusion about the loved one's treatments, condition, and signs and symptoms were commonly reported by caregivers in this study. Caregivers discussed experiencing inadequate communication with providers, among members of the healthcare team, and between facilities. Multiple studies have shown end of life caregivers' desire for more information or better communication about signs, symptoms, and treatments (Docherty et al., 2008). Caregiver understanding is often insufficient due to inadequate communication with healthcare providers (Docherty et al., 2008). Other research has shown caregivers perceiving communications with healthcare providers as inadequate as well (Kaasalainen et al., 2013; Sanders et al., 2008).

A study by Benkel, Wijk, and Molander (2014) examined the various ways nurses, nursing assistants, and physicians judged the insight and understanding of family members at their loved ones end of life. Families who avoided talking about the disease process were generally deemed to have poor insight. Additionally, like some of the caregivers in this study, they found that some family members deemed to have a poor understanding of their loved one's

condition were commonly aware of the disease process and symptoms but did not acknowledge the fatal consequences. This phenomenon mirrors the “not as bad as it seems” theme encountered in this sample. For example, despite knowing their loved ones were chronically ill or dependent on life support, some caregivers viewed their loved ones’ deaths as unexpected.

Medical terminology and timing of communication in the healthcare setting were sometimes perceived negatively by caregivers. It is important that patients and families do not view the nurse as using ostentatious language in order to impress them. Employing medical terminology or the technical names of pieces of equipment may not be intended in this way by nurses, as they are used to using this language when interacting with other healthcare professionals. However, families and patients may view this language negatively and prefer to speak in more simplified terms. Using simplified language can help increase the understanding of patients and families, allowing them to make more informed decisions. It may also increase trust in the nurse, as the patients and their families will not perceive the nurse as trying to impress them and will not be as likely to feel inadequate because they do not understand the terminology used.

Study Limitations

Sample

The original study used a convenience sample. Participants were recruited through an informal church leader, although not all participants were church members. Therefore, the sample may include more religious individuals than is actually representative of the population.

Methods

This study used preexisting data that was collected for a different purpose. The focus group discussions were primarily focused on caregiver decision making. While the caregivers frequently brought up their loved ones' signs, symptoms, and treatments, the research questions in the current study were not specifically addressed in the focus group discussion questions (Appendix B).

Additionally, the methods only allowed the researcher to examine the perceptions of the caregivers themselves. It is not possible to gather more information about the patient's actual conditions or the perceptions of healthcare providers, and we are limited to the caregiver's understanding of his or her loved one's signs, symptoms, and treatments rather than objective data or assessments by a health care professional. The caregiver's loved ones were also not present and the study is unable to provide information about their perspectives on their end of life experiences. Finally, all the caregivers in this study were caring for loved ones when they passed away or were seriously ill, so the data may not be able to be transferrable to patients who are not terminally ill.

Clinical Implications

There is a disconnect between caregiver and healthcare worker understandings of the patient's situation, and it is possible that providers are often not aware of incongruences. Individuals in the final stages of life are often cared for by informal caregivers whose interpretation of the patient's signs, symptoms and treatment needs and options may be incongruent with that of healthcare providers (Docherty et al., 2008). Nurses must take the steps

to narrow gaps in knowledge by using clear and simplified language, verifying information has been understood, and ensuring family is updated on the patient's plan of care and treatment options to consider, as there were many misunderstandings discussed by caregivers. The study identified various misinterpretations of signs, symptoms, and treatments. It is essential that nurses assess the knowledge and attempt to elicit the interpretations of family members and informal caregivers so that the nurse can correct any misunderstandings and clarify patient teaching. The nurse should ensure the caregiver receives and comprehends the information they desire about the disease process, prognosis, signs, symptoms, and treatments. This will allow caregivers to make informed decisions for themselves and their loved ones, increasing the chances of a positive caregiving experience and a good death for their loved one.

Nurses can be a part of the solution to caregivers who feel like their voices are not being heard or who feel like healthcare workers lack compassion. Understanding that this is a problem, nurses need to take steps to address caregiver concerns and update them on the progress they are making towards resolving conflicts. Nurses and others who are providing patient care should be up front and open about their goals and that the patient is their main priority. Nurses must recognize good service is expected, and they should take the steps they can to make families' voices heard. They should be sensitive to patient and family perceptions and the timing of paperwork or sensitive questions. Whenever possible, caregivers should be allowed time to think about their decisions, and the nurses should try to discuss the paperwork at an appropriate time for the patient and family.

Educational Implications

It is vital that nurses are taught about providing information to the caregiver and family as the patient wishes. The focus groups showed the breadth of caregiver roles in the lives of their loved one. They are often tremendously involved in care at home and decision making, and their perceptions of signs, symptoms, and interventions influence how they make their decisions. From the beginning of their education, nurses must be taught to make sure caregivers fully informed if this aligns with the wishes of the patient and family. This will allow them to be involved in informed decision making. In end of life care, this could help increase the likelihood of achieving a good death experience and family satisfaction with care.

Student nurses are in a stage in between the professional healthcare provider and the outsider's understanding of health care. As they are in the process of learning pathophysiology and may not have a lot of working knowledge of terminology, they may be more equipped to understand the perspective of families who are thrown into the foreign language and processes of the healthcare system when their loved one is terminally or critically ill. This may allow them to better understand some of the learning needs of families and what might be taken for granted as common knowledge among experienced nurses. Additionally, students and seasoned nurses should be taught how to communicate in ways that can be easily understood by those outside of the healthcare field and to eliminate unnecessary medical terminology in order to increase effectiveness of communication with caregivers and, as a result, satisfaction with care. There also should be a focus on teaching students how to ask the right questions in order to verify understanding and elicit family and patient interpretations of signs, symptoms and treatments.

Providing comprehensive and comprehensible information on signs, symptoms, and treatments and help prevent incongruences similar to those encountered in this study.

It would also be beneficial to ensure nurses are taught to discuss advanced care planning with community members. Within this sample, the caregiver and their loved one had not always seriously discussed end of life preferences before decisions had to be made. Beginning the process with families and encouraging these difficult situations early could help ease the burden of informal caregivers. If these topics are discussed ahead of time, the caregivers may feel more prepared when they have to make a decision for their loved one.

Research Implications

Further research could include perceptions of specific treatments or perceptions of signs and symptoms of a specific disease process. This could help address areas where communication is lacking and help formulate interventions to allow for clarification or better education on the topics. Additionally, it would be beneficial to further address evaluation of patient and family understanding of end of life signs, symptoms, and treatments. Docherty et al. (2008) began to identify the ways healthcare providers assess insight and understanding. It would be beneficial to have more research in the area and to generate a more standardized way of evaluating understanding that could be introduced where end of life patients are receiving care. It would also be useful to study how caregiver interpretations may influence willingness to select treatments that may improve quality of life over quantity.

This area would also benefit from studies that are not only retrospective, but those done in real time. Gathering data from conversations in the hospital, nursing home, or home care

setting would allow researchers to understand how healthcare information was communicated. It would also reveal information about the types of questions patients and families had and what they deemed important to discuss with healthcare providers. Additionally, it would be beneficial to explore more about the patient's perspective of signs, symptoms, treatments, and decision making and the relation to the caregiver's interpretations in future studies. Exploring patient and caregiver satisfaction in end of life care in relation to interpretations of signs, symptoms, and treatments could also allow better understanding of how to ensure a good death for end of life patients and their families.

Benkel, Wijk, and Molando (2014) examined hope as both a coping strategy and a form of denial as well as determining hope's relation to insight in end of life care. According to their research, providers felt it was necessary to provide more information when they felt a caregiver's hope was a form of denial. It would be beneficial to examine more closely to role of hope and coping among caregivers and determine how this may be related to interpretation of signs and symptoms as less severe than how a healthcare provider may interpret them. This information could allow healthcare providers to better assess caregiver insight and determine how to interact with families using hope as a denial or coping mechanism.

Little research in this area was found that focused specifically on the perceptions of caregivers who were Black. As research indicates end of life preferences tend to differ among non-Hispanic Caucasians and African Americans, it is important to address the potential influences on decisions, including caregiver perceptions (Wicher & Meeker, 2012). It would be

beneficial to further explore the perspectives of Black caregivers and their interpretations of end of life care.

**APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVAL OF
EXEMPT HUMAN RESEARCH**



University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Approval of Exempt Human Research

From: UCF Institutional Review Board #1
FWA00000351, IRB00001138
To: Norma E. Conner and Co-PI: Samantha M. Sermarini
Date: October 20, 2015

Dear Researcher:

On 10/20/2015, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review: Exempt Determination
Project Title: Black Caregiver Responses to and Perceptions of Signs, Symptoms, and Treatments at the End of Life
Investigator: Norma E. Conner
IRB Number: SBE-15-11688
Funding Agency:
Grant Title:
Research ID: N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the [Investigator Manual](#).

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

A handwritten signature in black ink, appearing to read "Patria Davis", written over a horizontal line.

Signature applied by Patria Davis on 10/20/2015 02:54:22 PM EDT

IRB Coordinator

APPENDIX B: FOCUS GROUP QUESTIONS FROM THE ORIGINAL STUDY

1. Talk about the type of relationship you had/have with your loved one.
2. Prior to your loved one's illness, did you have a decision making role with your loved one? What types of decisions did you make?
3. What type of care have you provided? Do you think the type of care you provided was a result of the relationship you had with your loved one?
4. What sacrifices did you have to make to care for your loved one?
5. How long was your loved one ill? How long were you involved in care?
6. Who helped you care for and make decisions for your loved one?
7. Did you and your loved one have a usual way that you came to a decision?
8. Did your loved one recover? If your loved one did not survive his or her illness, where did they die?
9. What types of treatment decisions were you involved in if any (i.e. resuscitation, life supportive measures)?
10. How did caring for your loved one make you feel?
11. Do you believe you had a duty to care for your loved one?
12. What are your personal feelings about treatment? At the end of life? Regarding blood/organ donation?

References

- Angelo, J., K., Egan, R., & Reid, K. (2013). Essential knowledge for family caregivers: A qualitative study. *International Journal of Palliative Nursing*, 19(8), 383-388. Retrieved from <https://login.ezproxy.net.ucf.edu/login?auth=shibb&url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2012233822&site=ehost-live>
- Angelo, J., & Egan, R. (2015). Family caregivers voice their needs: A photovoice study. *Palliative & Supportive Care*, 13(3), 701-712. doi:10.1017/S1478951514000522
- Benkel, I., Wijk, H., & Molander, U. (2014). How to estimate understanding: Professionals' assessment of loved ones' insight into a patient's fatal disease. *Journal of Palliative Medicine*, 17(4), 448-452. doi:10.1089/jpm.2013.0507
- Conner, N. E., & Chase, S. K. (2015). Decisions and caregiving: End of life among blacks from the perspective of informal caregivers and decision makers. *American Journal of Hospice & Palliative Medicine*, 32(4), 454-463. doi:10.1177/1049909114529013
- Docherty, A., Owens, A., Asadi-Lari, M., Petchey, R., Williams, J., & Carter, Y. H. (2008). Knowledge and information needs of informal caregivers in palliative care: A qualitative systematic review. *Palliative Medicine*, 22(2), 153-171. Retrieved from <https://login.ezproxy.net.ucf.edu/login?auth=shibb&url=http://search.ebscohost.com/login.aspx?direct=true&db=awh&AN=34102950&site=eds-live&scope=site>

Draper, A., Day, E., Garrood, E., & Smith, P. (2013). Patients and carers experience of living with a complex neurological and palliative diagnosis. *Mortality*, 18(3), 270-289.
doi:10.1080/13576275.2013.820177

Family Caregiver Alliance. (2012). Selected caregiver statistics. Retrieved from
<https://caregiver.org/selected-caregiver-statistics>

Feng, Z. L., Fennell, M. L., Tyler, D. A., Clark, M., & Mor, V. (2011). Growth of racial and ethnic minorities in US nursing homes driven by demographics and possible disparities in options. *Health Affairs*, 30(7), 1358-1365. Retrieved from
<https://login.ezproxy.net.ucf.edu/login?auth=shibb&url=http://search.ebscohost.com/login.aspx?direct=true&db=edswsc&AN=000292497600019&site=eds-live&scope=site>

Fluur, C., Bolse, K., Strömberg, A., & Thylén, I. (2014). Spouses' reflections on implantable cardioverter defibrillator treatment with focus on the future and the end-of-life: A qualitative content analysis. *Journal of Advanced Nursing*, 70(8), 1758-1769. doi:10.1111/jan.12330

Gao, X., Prigerson, H., G., Diamond, E., L., Zhang, B., Wright, A., A., Meyer, F., & Maciejewski, P., K. (2013). Minor cognitive impairments in cancer patients magnify the effect of caregiver preferences on end-of-life care. *Journal of Pain & Symptom Management*, 45(4), 650-659. doi:10.1016/j.jpainsymman.2012.03.003

General Medical Council. (2010). *Treatment and care towards the end of life: Good practice in decision making*. London: General Medical Council.

Godwin, B., & Waters, H. (2009). 'In solitary confinement': Planning end-of-life well-being with people with advanced dementia, their family and professional carers. *Mortality*, 14(3), 265-285. Retrieved from

<https://login.ezproxy.net.ucf.edu/login?auth=shibb&url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2010365963&site=ehost-live>

Harrington, A., Mitchell, P., Jones, J., Swetenham, K., & Currow, D. (2012). Transition to an in-patient palliative care unit: Carers share their experiences. *International Journal of Palliative Nursing*, 18(11), 548-552. Retrieved from

<https://login.ezproxy.net.ucf.edu/login?auth=shibb&url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2011893016&site=ehost-live>

Helmes, E., & Pachana, N. A. (2014). Carer levels of concern on driving and other activities in older people that put others at risk. *Australasian Journal on Ageing*, 33(1), 50-54 5p.
doi:10.1111/ajag.12041

Hsieh, H., & Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288. doi:10.1177/1049732305276687

Kaasalainen, S., Strachan, P., H., Heckman, G., A., D'Elia, T., McKelvie, R., S., McAiney, C., . . . Demers, C. (2013). Living and dying with heart failure in long-term care: Experiences of residents and their family members. *International Journal of Palliative Nursing*, 19(8), 375-382. Retrieved from

<https://login.ezproxy.net.ucf.edu/login?auth=shibb&url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2012233821&site=ehost-live>

Loggers, E. T., Maciejewski, P. K., Paulk, E., DeSanto-Madeya, S., Nilsson, M., Viswanath, K., . . . Prigerson, H. G. (2009). Racial differences in predictors of intensive end-of-life care in patients with advanced cancer. *Journal of Clinical Oncology*, 27(33), 5559-5564 6p.
doi:10.1200/JCO.2009.22.4733

National Hospice and Palliative Care Organization. (2014). NHPCO facts and figures: Hospice care in america. Retrieved from
http://www.nhpc.org/sites/default/files/public/Statistics_Research/2014_Facts_Figures.pdf

Noble, H., Kelly, D., & Hudson, P. (2013). Experiences of carers supporting dying renal patients managed without dialysis. *Journal of Advanced Nursing*, 69(8), 1829-1839.
doi:10.1111/jan.12049

Penman, J., & Ellis, B. (2015). Palliative care clients' and caregivers' notion of fear and their strategies for overcoming it. *Palliative & Supportive Care*, 13(3), 777-785.
doi:10.1017/S1478951514000571

Sanders, S., Ott, C. H., Kelber, S. T., & Noonan, P. (2008). The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Studies*, 32(6), 495-523. Retrieved from

<https://login.ezproxy.net.ucf.edu/login?auth=shibb&url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2009972374&site=eds-live&scope=site>

U.S. Department of Health and Human Services. (2010). Administration on aging (AoA): A statistical profile of black older americans aged 65+. Retrieved from

http://www.aoa.acl.gov/Aging_Statistics/minority_aging/Facts-on-Black-Elderly-plain_format.aspx

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis:

Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences*, (3), 398. Retrieved from

<https://login.ezproxy.net.ucf.edu/login?auth=shibb&url=http://search.ebscohost.com/login.aspx?direct=true&db=edsgao&AN=edsgcl.350099523&site=eds-live&scope=site>

Wee, B. L., Coleman, P. G., Hillier, R., & Holgate, S. H. (2006a). The sound of death rattle II:

How do relatives interpret the sound? *Palliative Medicine*, 20(3), 177-181.

doi:10.1191/0269216306pm1138oa

Wee, B. L., Coleman, P. G., Hillier, R., & Holgate, S. H. (2006b). The sound of death rattle I:

Are relatives distressed by hearing this sound? *Palliative Medicine*, 20(3), 171-175.

doi:10.1191/0269216306pm1137oa

Wicher, C. P., & Meeker, M. A. (2012). What influences African American end-of-life

preferences? *Journal of Health Care for the Poor and Underserved*, (1), 28. Retrieved from

<https://login.ezproxy.net.ucf.edu/login?auth=shibb&url=http://search.ebscohost.com/login.aspx?direct=true&db=edspmu&AN=edspmu.S1548686912100048&site=eds-live&scope=site>